

tem, and which, therefore, would subject the person who assisted them to legal jeopardy.

As a person with a physical disability (C2-3 quadriplegia), and as a researcher and attorney who studies health care and disability policy, I have strong feelings about the right to euthanasia. Since I was injured at the age of 16 (approximately 18 years ago), my most important objective has been to gain the fullest possible control over my life. This goal is not very different from that of many nondisabled people, but it is somewhat more difficult to achieve for people with no voluntary use of their arms, hands, and legs. Through advanced education and professional endeavors, I have been able to obtain substantial control of my life and, consequently, substantial satisfaction and happiness.

Unfortunately, many disabled people have not had these opportunities, and some live unhappy lives in which they have (or at least believe they have) little or no control. Three of my friends decided several years after becoming disabled that they no longer wished to live and committed suicide. One attempted suicide three times over a five-year period, twice wounding himself severely and painfully before successfully killing himself. All three ultimately were able to free themselves from lives they did not want. All three had sufficient functional capacity to complete the act without any assistance. For other disabled people who do not have such capacity, suicide is impossible. For them, voluntary euthanasia is the functional equivalent of suicide.

The ability to choose whether to commit suicide—to implement the decision to continue or discontinue life—constitutes the ultimate manifestation of control over one's life. People who believe they have no control over the fundamental decision to live cannot claim to have autonomy over their lives. Possibly in recognition of this, and because it is considered ludicrous by many to punish an attempt at taking one's own life, attempted suicide is no longer illegal in this country. We respect, or at least tolerate, the decision of a person capable of suicide to take his or her life. Yet we continue to prohibit people incapable of suicide from having another person assist them.

Beyond the various religious arguments, the primary contention against the legalization of voluntary euthanasia concerns its potential for abuse—that is, actual murder or emotional coercion to choose death. Appropriate safeguards to prevent such abuse can be built into a law permitting euthanasia. In the Netherlands, for example, there is no prosecution of euthanasia if a specific protocol is followed involving confirmation of the request made to more than one physician by the person wishing to die.^{6,7}

In reality, the prohibition against voluntary euthanasia in our society is based primarily on social paternalism. People with terminal illnesses or severe disabilities are considered by society incapable of making a rational decision to die. Yet, in truth, most disabled people are at least as capable as nondisabled people of making such decisions and, in the interest of self-determination, should be allowed to do so. As a person with a disability, I resent the prospect of physicians, judges, or public officials making decisions about me that are inherently personal and that fundamentally affect my life. Many other disabled people, as well as many nondisabled people, share this sentiment.

Thus, in the interest of autonomy and self-determination, voluntary active euthanasia should be legalized in this country. First, however, we must provide disabled people with the

supports they need to live in a dignified manner. Many disabled people require substantial resources, including personal assistance services, to live in their communities.⁸ Some are discouraged by national and state policies from attempting to live productively and independently.⁹ Without adequate resources and incentives, disabled people are given little reason to live. Many who are choosing suicide are responding rationally to a system that does not provide the supports they need (G. Kolata, "Saying Life Is Not Enough, the Disabled Demand Rights and Choices," *New York Times*, January 31, 1991, p B-7). Some do not want to live because they think they are imposing enormous caretaking and financial burdens on their families and friends.

Contrary to common belief, the vast majority of people with disabilities cherish life and are content to live with their disabilities until their natural deaths. It is likely that few would choose euthanasia if they had viable alternatives to meet their needs and to live with dignity. As a society, we must provide such alternatives. For those who ultimately decide that they do not want to live, we must respect their choice.

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Responding to Requests for Ventilator Removal From Patients With Quadriplegia

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RECENT ADVANCES IN MEDICAL TECHNOLOGY and the availability of emergency medical services have allowed an increasing number of people to survive serious injuries and catastrophic illnesses that permanently impair respiratory function and that require the lifelong use of mechanical ventilation. Spinal cord injury centers have developed remarkably effective special programs for the comprehensive rehabilitation of patients with high quadriplegia who require ventilator use.^{1,2} During follow-up interviews after rehabilitation dis-

(Maynard FM: Responding to requests for ventilator removal from patients with quadriplegia, *In Rehabilitation Medicine—Adding Life to Years* [Special Issue]. *West J Med* 1991 May; 154:617-619)

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charge from one of three such centers, 26 (87%) of 30 patients were residing outside an institution, 28 (93%) reported "being glad to be alive," and 19 (63%) rated their quality of life as good or excellent.

Despite these results and perhaps in response to greater societal interest in avoiding futile medical treatment, requests for ventilator removal by patients with quadriplegia who require ventilator use have become more frequent (M. Johnson, *Disability Rag*, September-October 1990, pp 16-26; P. Painton, E. Taylor, *Time*, May 19, 1990, pp 62-71).^{3,4} A broad spectrum of factors may contribute to a person's making such a request. Hopelessness and despondency about the future are common emotions. Although the origins for these feelings may be unique to each person's attitudes, values, and previous life experiences, inadequate resources for creating an acceptable life-style can also be the primary source for the desire to die. Thus, it can become difficult for health care professionals to discriminate between requests that reflect a reactive depression and those that represent the existential decision of a competent adult person. Because recent court decisions have made it clear that competent people do have the right to refuse medical treatment, including continued ventilator use,^{5(pp2-4)} physicians should plan in advance how to respond to patients' requests for this action.

Health care professionals responding to a request for ventilator removal by a person with quadriplegia must consider their own attitudes about the value of life for people with severe physical disability. Able-bodied people respond sympathetically to a request for ventilator removal because they may assume that they would feel the same if in similar circumstances. Nevertheless, it is important to consider the distinction between a request for permission to commit suicide by a patient with quadriplegia who does not require ventilator use and a request for ventilator removal by one who does. Some members of the independent living movement for people with physical disability have suggested that there is no competent person whose physical disability is so extensive that the person could not end his or her own life without assistance from another person. They assert that withdrawing life-sustaining treatment from people with a stable, if severe, physical disability reflects an attitude of discrimination toward and devaluation of people with disability (A. Ruggeberg, Gazette International Networking Institute's Fifth Annual Conference on Independent Living and Post-Polio Rehabilitation, oral communication, June 3, 1990).

With sensitivity to this position and the historic commitment of the medical profession to preserving life, a simplistic affirmative response to a request for ventilator removal by an apparently competent patient with ventilator-dependent quadriplegia is inappropriate. The first consideration before formulating a response to such a request is determining whether the patient is expressing suicidal ideation or has made a thoughtful choice to discontinue life-sustaining treatment. There is an important distinction between these two. In the study previously cited of patients with high quadriplegia using ventilators, 50% reported suicidal ideas, such as "wishing to be dead."¹ By contrast, it is unusual for a patient to state clearly and emphatically, "I want to be taken off the ventilator now, and I know what this means." Health care professionals frequently ignore initial requests for ventilator removal because they are uncomfortable dealing with such requests. Responding to a serious request for ventilator removal in the same way as responding to suicidal ideas may

appear to trivialize such requests and offend the patient. Responding to requests for ventilator removal by discussing the common occurrence of death wishes can be helpful and can reassure a despondent patient. Misinterpreting a thoughtful request as an expression of temporary depressive thoughts must be avoided.

When it is clear that a patient is serious about requesting ventilator removal, it becomes important to acknowledge the legal right of patients to refuse medical treatment. United States courts have consistently ruled that competent patients with unremediable conditions requiring ventilator use have the right to be removed from ventilators.^{5(pp2-4)} The purpose of acknowledging this legal right, as a patient's attending physician, is to avoid a battle of wills. When a physician says, "We cannot allow you to do this," a person's resolve to be removed from a ventilator is more likely to increase. This response accentuates feelings of loss of control, and these feelings are high among people with extreme physical dependency. By acknowledging their right, physicians will not unintentionally encourage patients to pursue proving they ultimately have the legal right to decide their own fate. Furthermore, if a battle of wills can be avoided from the beginning, some people may get through their hopelessness and change their mind about wanting to live. The case of McAfee (P. Painton, E. Taylor, *Time*, May 19, 1990, pp 62-67) supports this view because he has so far chosen not to discontinue ventilator use after successfully pursuing permission from the Georgia Supreme Court to do so. Distressed patients may occasionally try to gain sympathetic attention from family or care givers with an expressed wish to die. Taking these patients' requests at face value can sometimes expose their manipulative purpose.

After discussing the right to refuse continued treatment, I usually recommend that several action steps be followed by the patient and by the attending physician before a request for ventilator removal be honored in order to preserve the ethical integrity of the medical profession and to maintain respect for a patient's autonomy.

Action Steps for Patients

- Obtain independent legal counsel. Most patients and families know how to do this and only need permission and encouragement to do so. Other patients may need help to find legal counsel, and fees may be problematic.
- Discuss the request with family, significant others, and spiritual counselors. The patient must be given ample opportunity to communicate thoughts and emotions with as many people as possible about his or her current condition and available options for the future.
- Meet with peers and learn about their lives. A peer is a person who has a similar physical condition and ideally is of the same sex and social, economic, and educational background. Although it can be difficult to find a perfectly matched peer, anyone who is living successfully while continuing to use a ventilator can be helpful, and it is critically important that the patient meet and communicate with such people.
- Learn about all possible rehabilitation outcomes. Patients and families must have exposure to a wide variety of educational resources about and options for rehabilitation. Possible goals for rehabilitation and independent living, and the process needed to reach them, must be explained and understood.

- Participate in independent psychological evaluations. These assessments must be done to establish a person's competency for making decisions about his or her own welfare. Patients must comply with these interviews and demonstrate knowledge about their condition, the implications of having their request granted, and about all available options for continued care.

Action Steps for Attending Physicians

- Consult with a medical ethics committee. Most hospitals today have a multidisciplinary medical ethics committee. Members of these committees can provide emotional support for professionals, address both moral and legal concerns, and provide insights from many perspectives.

- Discuss plans and concerns with all members of the health care team. It is vitally important that everyone involved with a patient's care understand what is happening and that all team members work together. Everyone's feelings need to be acknowledged, and all must be reassured that they will not be asked to violate their own moral integrity.

- Maintain communication with the patient and family. If dialogue continues, every opportunity for the person to retract the decision to die can be ensured. All interested parties can also make their concerns known, and severe emotional pain after the termination of life support can be lessened.

- Enable patients to complete their action steps. They may need considerable support and firm encouragement to engage in these action steps. They may also need assistance and resources to complete some of them.

- Formulate an opinion about a patient's capacity for making decisions about his or her own welfare. The Hastings Center has recommended that a "process standard" be used for determining the capacity to make such decisions.^{5(pp130-133)} Health care professionals may have appropriate concerns that a patient's decision is a result of temporary reactive depression. The patient may not be able to evaluate the situation rationally and make a competent decision that is not simply reflecting feelings of hopelessness. Applying the process standard can ensure that a decision is responsible and well thought out. By giving the patient some action steps to carry out, the physician can observe the patient's behavior over time. During this time, when an attorney is contacted, interviews take place, information is provided, and a discussion occurs with other people, the patient's capacity to understand available choices and the implications of the decision can best be determined by the attending physician and the health care team.

In summary, there is therapeutic value in respecting patients' autonomy and right to refuse treatment as an initial response to requests for ventilator removal by patients with ventilator-dependent quadriplegia. Knowledge that the decision is ultimately their own may make such patients more likely to change their mind with the passage of time. Nevertheless, patients with strongly expressed desires to withdraw mechanical ventilation may have a high probability of dying regardless of what action is taken by professionals. Patients who have mechanical ventilation withdrawn and who reject the quality of life offered by medical rehabilitation may create strong feelings of futility and low self-worth among health care professionals whose work strives to enhance the quality of life for these patients. The paradigm of indepen-

dent living, however, emphasizes the central role of individual self-determination, irrespective of complete physical helplessness.⁶ Therefore, when persons who have tested life with ventilator-dependent quadriplegia after optimal rehabilitation or who have thoughtfully considered all of their options make a responsible choice to withdraw treatment and end life under these circumstances, the decision can be viewed as consistent with the traditional goals of medical and rehabilitative practice.

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Living With a Ventilator

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"I'M NO DIFFERENT from you. I'm just sitting down."¹ The statement was made by a 25-year-old man with Duchenne's muscular dystrophy during a taped interview with a psychology student. On initial inspection, his gaunt face led the interviewer to think that there were many differences between them—many more than simply their position in space at that moment. The powered wheelchair that he controlled with his tongue and that held the mechanical ventilator beneath its solid frame made their lives seem more different than anything they could possibly have shared. Yet as the interview progressed, they found that they shared many of the same dreams, goals, and interests. Music gave each great comfort. And relationships with people had caused both the greatest pains and the greatest pleasures in life. The soft hum of the ventilator as it momentarily interrupted his speech became less noticeable as the interview progressed. Indeed, he also became less different. His life, though more arduous, was one that he valued no less than the interviewer valued his own. He wished that his choices had included whether he needed to have muscular dystrophy or not, but that was never an option. The choice as to whether he wanted to continue his life by using a ventilator when his muscles failed him—well, he made that choice, and he did not regret it.

The use of a ventilator as a treatment modality for patients with chronic disease began with the polio epidemics of the 1940s and 1950s.² For many patients with acute respiratory failure of polio, reality became life forever dependent on a machine. Many of these survivors went on to find successful

(Gilgoff IS: Living with a ventilator. *In* Rehabilitation Medicine—Adding Life to Years [Special Issue]. *West J Med* 1991 May; 154:619-622)

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